

NEWSLETTER

AIDS NETWORK OF EDMONTON SOCIETY

July/August 1988

Volume 3 No. 6

Network/U of A Establish Research Fund

The AIDS NETWORK Research Trust Fund has been established at the University of Alberta for AIDS research. The fund, which will be administered by an advisory committee chaired by the Dean of Medicine, will provide money for projects for both basic and applied research on AIDS as well as any aspect of HIV infection. Research will include all aspects, from basic virology in a laboratory to psycho-social and community concerns.

"Optimal care of local people with AIDS", according to Dr. Larry Jewell, NETWORK Chairperson, "is best ensured by an active research program here at the University of Alberta. The AIDS NETWORK Research Trust Fund will provide the mechanism for receiving funds that would otherwise go out of province."

One of the first donations received by the NETWORK for AIDS research was \$16.67 from the Trinity United Church Explorers troupe. As well, \$2,500 from the February AADAC/AIDS NETWORK AIDS Conference has been donated to the fund.

Michael Schreiner, Vice Chairperson of the NETWORK Board of Directors will represent the NETWORK on the advisory committee, with Kate Thompson, Board member, serving as an alternate. Donations to the fund, which are eligible for provincial matching grants can be made through the AIDS NETWORK office. All donors will receive a tax-deductible receipt.

ROSS ARMSTRONG MEMORIAL FUND

UPDATE - JULY 1988

Donations:	\$4,918.35
Memberships:	\$4,075.00
Interest:	\$ 216.42
Sub Total	\$9,209.77

Grants:	\$5,092.32
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NET:	\$4,117.45
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In Memorium

In the midst of long summer days, loud thunderstorms, warm evenings and our own busyness, we take a moment to remember our friends Ross Armstrong, Dean and Eric who left us in the summer of 1986. Their love, laughter, and courage still inspire us.

As well, we note the death of David this month. The NETWORK staff and volunteers extend sympathy to his friends and family.

Rethinking AIDS definition

by Michael Specter
Washington Post Staff Writer

So many kinds of illnesses have been traced to the AIDS virus that leading researchers have concluded that the term "AIDS" no longer adequately describes the nature or magnitude of the epidemic.

They now regard acquired immune deficiency syndrome as only the most dramatic and visible form of a complicated disease and think that AIDS has become a misnomer based on symptoms rather than infection. Instead, many argue that the epidemic should be renamed after the virus that causes it: the Human Immunodeficiency Virus (HIV).

The Public Health Service estimates that as many as 1.5 million Americans have been infected with the virus, almost 30 times the number of those who have been diagnosed with AIDS. A growing body of scientific evidence suggests that most--perhaps all--of those infected will get sick. And recent research shows that the virus often causes serious damage even to those who seem healthy.

"It has been clear for some time that the real epidemic starts when you become infected with HIV," said William Haseltine of the Harvard University School of Public Health. "AIDS is just the most severe manifestation of that disease, but there are many more and they can kill you, too."

AIDS-related complex (ARC), for example, has made tens of thousands of Americans gravely ill and has killed many others. But because the Centers for Disease Control (Atlanta) has established a specific definition of AIDS, those who die from ARC are not normally included in the weekly count of AIDS cases.

In addition, recent studies have suggested that HIV causes a loss of mental function (dementia) long before other symptoms of AIDS surface.

As they learn the many ways HIV can assault the body, physicians have begun to disregard the official definition of AIDS, saying that they find it of little use in treating patients. Although the CDC approach remains the standard one for tracking the disease in the population, newer methods give a far better picture of the damage the virus causes.

The CDC system relies heavily on specific symptoms and illnesses associated with HIV infection for its definition of AIDS. It was established before researchers had discovered that HIV caused AIDS. And it has been modified several times in the past five years.

Last year federal officials expanded the definition of AIDS to include dementia and emaciation among the illnesses that are recognized as caused by HIV infection.

Until then, to be diagnosed with AIDS a person would have to show evidence of a damaged immune system and the presence of at least one of the officially recognized cancers or opportunistic infections, such as Kaposi's sarcoma or pneumocystis carinii pneumonia.

But Army doctors have developed a system that evaluates subtle changes HIV causes in the blood of infected people that harm key parts of the immune system. Specialists, including those at CDC, say that it does a better job of measuring the effects of the disease among individuals.

HIV slowly destroys the immune system by attacking the cells responsible for leading the body's defense against illness and in some cases by invading the central nervous system.

Under the CDC system, 20 to 30 percent of those infected with HIV will develop AIDS within three to five years of infection. But the staging system developed by the Walter Reed Army Institute of Research tells a far more alarming story.

"Walter Reed doesn't look at symptoms as much as it looks right at what HIV has done to the immune system," said Dr. Anthony S. Fauci, director of AIDS activities for the national Institutes of Health. "It shows that the vast majority (of those infected) have some deleterious effect of the virus within five years."

Researchers at Walter Reed and other medical centers around the country who have studied the depletion of the type of blood cells that protect the immune system have found that at least 90 percent of infected individuals will suffer demonstrable damage to those cells within three to five years.

That means HIV begins to cause serious damage to most infected people long before the symptoms of AIDS appear and often before people become aware they have been infected. And it suggests that treatment cannot wait until symptoms become evident.

CDC officials say that the definition of AIDS has been developed for reporting and public health purposes only. They draw a distinction between how individual patients should be treated and how the epidemic should be assessed statistically as a public health threat.

"There is nothing magic about the CDC system," said Dr. Harold Jaffe, chief of AIDS epidemiology there. "We created it for a specific purpose - to monitor trends in life-threatening manifestations of HIV infections. As we know more about those trends, we will amend the system."

Last year's revisions raised the number of AIDS cases by nearly 15 percent and enabled thousands of people to qualify for Social Security disability payments and other benefits reserved for AIDS patients.

But for thousands of others the revisions did nothing. Federal health officials estimate that there are as many as 10 people with ARC, for every one with AIDS.

Many of them are without detectable symptoms. But others can be gravely ill and still not qualify for the automatic benefits that people with AIDS can get.

Because its symptoms vary so greatly, ARC is difficult for many physicians to define. Its meaning can vary greatly, and there are huge discrepancies in the use of the term. The term has never been officially recognized by CDC for reporting purposes.

"ARC really isn't a thing," said Christine Gebbie, chairman of the AIDS task force for the Association of State and Territorial Health Officers and a member of the presidential commission on AIDS. "It's a bunch of letters that happened because we could see sick people who needed to be described in some way. But they did not fit the definition of AIDS. It tells us very little about the disease. And I am sure its use will diminish as we learn more about HIV."

Because ARC can so easily be confused with other illnesses, such as hepatitis or mononucleosis, few states report it. But ARC patients often exist in a painful netherworld: They are too sick to work but cannot easily qualify for Social Security benefits.

Several studies have shown that people infected with HIV who do not yet have AIDS experience greater levels of stress and anxiety than people with AIDS. In many cases, the pressure of waiting to get sicker appears greater than that associated with the illness itself.

The elaborate systems that have been developed to describe the disease HIV causes are outmoded, according to Dr. Samuel Broder, chief of clinical oncology at the National Cancer Institute.

"The virus would certainly be shocked if it could understand how we have chosen to classify it," Broder said. "It's like people who don't want to move to a bigger house but keep building on new rooms. The place can look a little odd after a while."

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May/June 1988 - Volume 3:4

Upcoming events

August

The Imperial Court of the Wild Rose will host an international conference and ball on August 6th, 1988. For more information please phone 428-9444.

September

Nexus Theatre will host a benefit for the AIDS Network of Edmonton Society presenting Gertrude Stein and a Companion on September 5th, 1988 at 68 McCauley Plaza - Phone 429-3625 for tickets.

The AIDS Challenge a seminar about the concerns of the health care community regarding AIDS; Wednesday, September 18th, 1988 - 10 a.m. - 5:30 p.m., Bernard Snell Auditorium, Mackenzie Health Sciences Centre - U of A Campus. For more information phone: 432-3116.

AIDS and Care: a Pastoral Care Workshop in conjunction with the AIDS Vigil of Prayer September 14th at the Unitarian Church, 1 p.m. - 4 p.m.
Registration \$5.00 - Phone 488-2496 for information.

Prayer Vigil for AIDS - September 16 - 18th.

"A Community Empowered by Prayer"
50 Hours of Silent Prayer and Meditation at Edmonton General Hospital Chapel beginning Friday September 16th at 7 p.m. Use 100 Avenue entrance.

Sept. 16th - Opening Ecumenical Service at Garneau United Church, 11148 - 84 Avenue, 7 p.m.

Sept. 18th - Closing Prayer Service at Metropolitan Community Church Edmonton, Unitarian Church, 12530 - 110 Avenue, 7 p.m. - Reception to follow.

October

AIDS CONFERENCE - "Don't Cast Me Away" sponsored by the Department of Psychiatry, Misericordia Hospital on October 27 and 28th, 1988 at the Convention Inn, 4404 Calgary Trail, Edmonton. For more information contact Nursing Practice Office - Misericordia Hospital - phone 484-8811 ext. 832/889.

Make a choice

Albertans are being asked to "Make a Choice", Don't Take a Chance" in a series of three television ads on AIDS produced by ALBERTA COMMUNITY AND OCCUPATIONAL HEALTH.

Research conducted by COH indicates high levels of knowledge about AIDS and how to prevent it among the general public. The ads aim to encourage people to use their knowledge in preventing the spread of AIDS.

The ads are the latest in a series of Community and Occupational Health initiatives against AIDS, which includes funding of community groups like AIDS Network, establishing a province-wide information line, assisting Alberta Education with the creation of an AIDS curriculum, and funding numerous publications about AIDS.

The ads were produced by Scali, McCabe, Sloves and shot at ITV Edmonton's new sound stage.

By: Bill Carney
Community and Occupational Health

Support for you

Have you tested positive for HIV?

Maybe you don't have a positive test or have not been tested and maybe you are concerned about your health status or perhaps you are concerned about a friend or lover or relative.

Are you anxious about your relationships, your privacy, your job security, your family relationships, your ability to cope in the age of AIDS?

Do you know where to go for help?

We can meet you in the community, at a coffee shop perhaps. We can also just talk on the phone. No pressure - just supportive listening and discussing options.

CANADIAN AIDS CONFERENCE --

four perspectives

In mid May, Board members and staff of the ANE attended the Canadian AIDS Conference in Toronto. This national conference with the theme, Uniting Perspectives for Prevention and Caring in the Community was a joint effort of the Federal Centre for AIDS, Health and Welfare Canada, The Canadian AIDS Society and the Canadian Public Health Association. Key AIDS programmers and field staff from across the country came together to share their experience and enhance the national effort against AIDS.

The following are four perspectives of the conference by NETWORK board members and staff:

Although this was not the first national conference sponsored by the Canadian AIDS Society, it was the first time that some of the crucial "players" in the fight against AIDS got together. Both the community groups and the public health profession were well represented, and there were a few of the most senior decision makers from provincial and federal governments. Clinicians involved in direct patient care and researchers were not well represented, but we hope that they'll be there at the Montreal Conference in 1989. I felt that although interactions were angry and uncomfortable sometimes, it was absolutely necessary and on balance people seemed to come to a recognition that we have much to learn from each other. The necessity of funding existing educational initiatives, as well as the urgency of dealing with the spread of HIV into the IV drug use community was felt by all.

Dr. L. Jewell, Chairperson-Board of Directors

I saw the Toronto Conference on AIDS as a watershed event - one that shook federal officials right off their bureaucratic feet. With fire and passion plenary speakers roundly chastised the inaction and foot-dragging that has marked our national AIDS policy.

In this context the break-out sessions were slightly anti-climactic. Good information was readily available, and each session reinforced the notion that in order to effect changes in behavior, AIDS education must become more creative.

Finally to our growing list of target-groups which need education about the perils of AIDS, it appears we need to add one more : politicians.

Nandini Kuehn - Education Consultant

The opportunity to meet with individuals across Canada who are involved in support was certainly outstanding. Being able to leave Toronto with names of individuals who might be future resource persons was a great benefit. I think back on the few minutes I spent with Andrew Cruikshank, director of Casey House, and the perspective on care I gleaned from him. As well, the time I spend with workers at AIDS Committee of Toronto (ACT), AIDS Committee of Montreal (C-SAM) and other individuals very much confirmed the level of service we provide.

Within the workshops I again reflect on the information shared which I feel affirms the programs we have in place.

The point which was stated quite clearly was that dealing with HIV/AIDS is a collaborative effort, a shared learning and growth experience.

David Fitzgerald-Support Services Co-Ordinator

For me, the most powerful message was the call for educators to speak with a clear simple message and to speak in positive terms.

Telephone hotlines across the country were identified as key, non-judgemental ways to reach otherwise unreachable people. Delegates noted that their operators increasingly deal with more complex and lengthy calls, but see the calls as "teachable moments."

The challenge to everyone is to get out there with the message - lives depend on it.

Guy Milner - Board of Directors

Network education initiatives

This summer and fall, the NETWORK will be involved in a number of education and information projects and initiatives designed to promote safer sex and AIDS prevention, alleviate unnecessary fears and concerns, and raise the NETWORK's profile within the community.

- The NETWORK will be rotating our display and information throughout Edmonton's gay community, taking advantage of the special events generated by the International Court Ball conference. Special door prizes of a deluxe safer sex kit will be donated by the NETWORK at various functions and we are encouraging more individuals to sign up to receive our newsletter.
- The NETWORK will sponsor a booth at the Folk Festival this year, as well as our usual booths at Klondike Days and the Fringe. Our display theme this year will invite people to "Shatter the Myths" and explore how AIDS affects them.
- A donation of advertising space in the downtown LRT stations will be used by the NETWORK to tell people that "Mosquitoes DON'T carry AIDS". A pamphlet will also be produced around the facts and myths of AIDS transmission for our summer displays.
- This fall, the slogan "8 Albertans could be infected tomorrow" will appear on the tailgates of Edmonton Transit Buses. The number of daily infections is based on a study which projected 3000 new HIV infections in Alberta in 1988.

Discrimination complaints will be heard

The Canadian Human Rights Commission (CHRC) announced May 25th in a policy paper it will deal with complaints of discrimination against people with HIV infection, people who may be perceived to be infected, and people who may associate with those infected.

Dr. Larry Jewell, Chairperson of the AIDS Network of Edmonton Society praised the Commission for taking action "against a problem that we have been fighting for years -- ignorance and fear leading to discrimination of people affected by AIDS -- people carrying HIV, their families, friends and/or lovers."

Three requirements for HIV testing

The CHRC states clearly that irrational fears on the part of employers or employees, no matter how widely felt, do not constitute grounds for discrimination. The Commission also states that it will recognize three "bona fide occupational requirements" as justification for HIV testing -- people who carry out "invasive"

procedures, people traveling to countries which bar entry to those who are HIV-infected and when "sudden deterioration of the brain or central nervous system" would compromise safety standards. "We hope", said Dr. Jewell, "that this will not be misunderstood as circumstances where mandatory testing is warranted."

Dr. Jewell expressed his disappointment that the Commission doesn't oppose mandatory testing for everyone, although Chief Commissioner Maxwell Yalden did state that "there is no public health reason to invade people's privacy in this way without their consent and without good reason for doing so".

Network disappointed

The NETWORK and other concerned agencies have begun a dialogue with provincial authorities to establish legislation protecting Albertans from discrimination due to HIV infection.

Our volunteer program

Volunteers with the AIDS Network of Edmonton Society are as diverse in age, background and interests as the general community. A common motivator however is to be involved in a social issue which is urgently needing attention.

Ambassadors and Advocates

Stan, Irene, and Max have been invited as "seasoned" volunteers to speak about their volunteer experiences to a new group of volunteers-in-training who are taking the 34-hour training sessions required of all volunteers. Stan, a self-assured young man in his 30's nods his head and smiles quietly as he listens to the group share what has motivated them to want to be a volunteer for the NETWORK. He recalls how a lack of information and a concern about this new social issue motivated him to get involved in making a difference on how the public perceives people with AIDS. Through his involvement with the Speakers' Bureau and as a member of one of the seven committees in the agency, he has a greater insight into the work done by the NETWORK through its education and support service programs. This makes him an eager ambassador and advocate for the NETWORK in the community.

A young woman dressed like a university student speaks to the group next about her volunteer experiences as a hospital visitor. Weekly Irene visits clients of the NETWORK who are receiving medical care in one of the local hospitals. Her expression of concentration and compassion rivets the audience as she speaks of meeting individuals who have shown so much courage and determination as they grapple with living with this disease. Irene tells how humbling and yet gratifying this experience has been and how it has given her an opportunity to clarify her own values and views about life. Stan reminds Irene that she has

also met some pretty exceptional people in her fellow volunteers. Everyone joins in the laughter. Irene describes how she initially trained on the telephone information line and did office work for a while until she was comfortable with her knowledge about the agency and about AIDS to begin hospital visiting. In the future she hopes to be matched with a "buddy", a person with AIDS, whom she can befriend and give emotional support to.

Max, a softspoken man in his 40's has been listening attentively. As another volunteer he begins to share with the group his experiences of watching a former lover develop the first symptoms of AIDS. Over the next 13 months he is on a rollercoaster of emotions as his lover progressively gets sicker and eventually dies after yet another bout of pneumonia. Although this happened two years ago Max's eyes still fire up with anger and frustration as he recalls how difficult it was for his former lover to access services and how his family withdrew support as he became sicker and more debilitated.

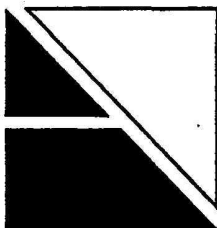
Monthly inservice evenings

In beginning to close this training session, Brigitte, the Coordinator of Volunteers, adds that one essential component of the volunteer program is the built-in support and ongoing educational opportunities available to volunteers. At monthly inservice evenings guest facilitators present topics pertinent to volunteers. As well, volunteers plan a monthly social evening to keep in touch with one another. Support meetings for volunteers working in specific areas are held monthly to share concerns, and issues and to get support from another.

The next volunteer training sessions will be offered in late September. Any persons interested in becoming a volunteer should contact Brigitte or Doris at 424-4767.

Office Address:

10704 - 108 Street
Second Floor
Edmonton, Alberta
T5H 3A3



Telephone Number:

Info Line: 429-AIDS (2437)
Business Line: 424-4767

Office Hours:

Monday - Friday 9 am - 6 pm

Information Line Hours:

Mon - Thurs 9 am - 9 pm
Friday 9 am - 6 pm
Saturday 11 am - 3 pm

The newsletter is published monthly by the AIDS Network of Edmonton Society with financial assistance from the HEALTH PROMOTION DIRECTORATE OF HEALTH AND WELFARE CANADA.

The AIDS Network of Edmonton Society, incorporated in February, 1986, is a registered non-profit charitable organization (Reg. # 0747212-11-25).

Donations to AIDS Research can be made through the AIDS Network Trust Fund, administered by the University of Alberta. Donations may be matched by provincial funds, and a charitable receipt is available.

The mandate of the AIDS Network is to provide support to those affected by AIDS and to educate and inform with a view to limiting its spread.

INFORMATION

An informational and support telephone line operates Monday - Saturday. Pamphlets and a lending resource library is available to agencies and the public.

EDUCATIONAL

A speakers' bureau provides speakers for educational presentations to concerned groups.

Audiovisual materials and information files are available on loan.

COUNSELLING

Confidential one-on-one professional counselling services are available to persons directly or indirectly concerned about AIDS. Referrals to other professional services are made upon request.

SUPPORT GROUPS


For persons who have tested positive for HIV antibodies; for person with AIDS; for friends, families and partners of persons with AIDS.

ADVOCACY

Assistance will be provided to individuals facing difficulties in receiving services because of their health status.

The AIDS Network works to coordinate the services of supportive public and private agencies in all areas involved by the AIDS crisis.

The services of the AIDS Network of Edmonton Society are provided FREE and on a CONFIDENTIAL basis.



Ross Armstrong Office, 2nd Floor, 10704 - 108 Street,
Edmonton, Alberta T5H 3A3
(403) 424-4767

AIDS NETWORK OF EDMONTON

APPLICATION FOR MEMBERSHIP

Name: _____

Address: _____

City: _____ Postal Code: _____ Phone: _____

A \$25⁰⁰ membership entitles the undersigned to discount admission at specified AIDS NETWORK events, regular newsletter mailings, and the right to vote at AIDS NETWORK meetings.

Signature: _____ Date: _____

Please notify the AIDS NETWORK if your address changes.

Please enquire about the reduced membership rates for students or the unemployed.



The AIDS Network of Edmonton Society is a member of the CANADIAN AIDS SOCIETY/LA SOCIÉTÉ CANADIENNE DU SIDA

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